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UNIVERSITY OF ALBERTA

THE EXPERIENCES OF HIV POSITIVE WOMEN IN THE HEALTH CARE SYSTEM

BY

LIANA JILL TURNER

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfilment of the requirements for the degree of MASTER OF EDUCATION

IN

COUNSELLING PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

FALL, 1995

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Date: September 28, 1995

ABSTRACT

The purpose of this study was to examine the experiences of HIV positive women in the health care system. There is no current research in this area and it is infeasible to compare the experiences of women to HIV positive men or people with cancer. Five HIV positive women were interviewed and they ranged in age from 19 to 36 years. The length of time the women had known they were HIV infected ranged from between 2 and 6 years, with an average time of 4 years. A phenomenological methodology was utilized and a thematic analysis of the participants' interviews ascertained 13 themes. The final thematic structure presented 3 themes believed to represent HIV positive women's experiences with health care. These 3 themes are Nature of health care, Importance of support and emotional health, and Wilful living: Self-determination. Implications of these findings for future research and for the health care system are discussed.

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CHAPTER ONE

INTRODUCTION

Although women comprise the fastest growing group of HIV infected people (Buckingham & Rehm, 1987; Campbell, 1990; Ide, Sanford, & Alpern, 1992), relatively little research has been conducted on the experiences of these women. Much of the research in the area of HIV/AIDS has come from research with gay men (Cochran & Mays, 1991). For instance, gay men served in studies designed to increase our understanding of the epidemiology and possible treatment of the disease. Therefore, little is known about the effects or consequences of the disease on women.

Since there is still a widespread belief that AIDS does not affect women (Ide et al., 1992) little is known about the course of infection in women. As a result, it is difficult for physicians to acknowledge the common manifestations in women, such as, pelvic inflammatory disease, endometriosis, cervical cancer, breast cancer, vaginal candidiasis, and urinary tract infection (Berer, 1993; Denenberg, 1990; Taylor-Brown, 1992) as these illnesses are not recognized and defined by the U. S. Centres for Disease Control (CDC) as HIV and AIDS related diseases and illnesses. Consequently, because these diseases are not recognized by the CDC, women who are diagnosed with AIDS tend to die twice as quickly as men, and

66% will die of HIV and AIDS complications without having been diagnosed as having AIDS (Ide et al., 1992).

The CDC reported that women make up 66% of all heterosexually transmitted AIDS cases. They also reported that these women have largely contracted the disease from drug users or bisexual men. The CDC's report also claimed that their figures show that the growth of AIDS cases among women outpaced those among men by about 50% ("New AIDS", 1994). Ickovics and Rodin (1992) offer two explanations as to this increased risk for women contracting the virus. First, the number of infected men is greater than the number of infected women which increases the probability that a woman would encounter an infected sex partner. Second, male-to-female transmission may be more efficient than female-to-male transmission due in part to a greater exposed area of mucosal surface in the female genital tract.

A woman may also be at a higher risk for contracting the HIV disease as her decisions regarding condom use may be compromised due to her reluctance, her partner's resistance, and the threats of rejection or physical abuse which may ensue if her partner does not want to use a condom (Cochran & Mays, 1989). Consideration must be given to the fact that traditional sex-roles and economic difficulties make it difficult for women to change their sexual or behavioral practices that put them at risk. Some women lack the information, tools, and power over their own bodies to

enable them to lessen the risk of infection (Carovano, 1991). In addition, women may not realize that they are at risk because they themselves do not belong to groups that may engage in high-risk activities. Many women may not be aware of the sexual behavior or drug use of their sexual partners and may erroneously believe that they are in a relationship that is risk-free (Smeltzer & Whipple, 1991).

Diagnostic differences, biological differences, and high-risk behaviors are not the only differences between HIV infected men and women. Ickovics & Rodin (1992) discussed that because of life-styles and life situations, women and men most at risk for AIDS are probably exposed to quite different life stressors. High-risk women are more likely than high-risk men to be poor, and poverty often results in inadequate housing and barriers to health care. Usually, women are more likely than men to experience higher levels of depression and anxiety. Also, women with AIDS are likely to be the sole care givers to their children and as a result, are less inclined to care for their own health while they are caring for their children.

Since women are the fastest growing segment of HIV infected people, they are entering the health care system in increasing numbers. Because there is no known research in the area of HIV infected women and their experiences in the health care system, it is an important area for investigation. As a result, further research with HIV

infected women will enable health care professionals to improve their care of women and ensure that their needs are being addressed and that they are receiving appropriate care.

Although there has not been research with HIV positive women in the health care system, there has been some research on the experiences of HIV positive men and health care. This limited research has indicated that these men attributed their good health to the belief that they can influence their health and that they are personally responsible for their health care (Solomon, Temoshok, O'Leary, & Zich, 1987). Similarly, there is a body of research with cancer patients which discusses the importance of patients' taking an active role in their health care (Roud, 1986). In addition, research on the attitudes of health care professionals has indicated that practitioners fear contagion with patients and experience anxiety when working with AIDS patients (Wallack, 1989). Wallack's research revealed that 9% of the health care workers surveyed reported that AIDS was God's punishment and 6% felt that gay men were deserving of AIDS. It is quite probable that as a result of these fears and attitudes, patients' health may be compromised by the practitioners who feel that infected people are to be feared and are deserving of the virus.

There is a need for research in the area of HIV

positive women and health care as women have distinct health care needs and their experiences can not be extrapolated from the unique experiences of HIV positive men. In addition, women differ from men in regards to education, socioeconomic status, route of transmission, and familial responsibilities. It is also infeasible to compare the health care experiences of HIV positive women to those of cancer patients because of the stigma of AIDS. This stigma adds a layer of fear and discrimination to the experiences of infected women.

The purpose of this current research is to throw light on the experiences of HIV positive women. This research augments the literature in the area of women's experiences in the health care system and addresses the needs that the women have as they enter the health care system in record numbers. Five HIV positive women were interviewed about their experiences in an open-ended interview format that initiated from the statement "Tell me about your experiences as an HIV positive woman in the health care system".

This present research describes the firsthand experiences of HIV infected women in the health care system through the perspective of women who have been directly involved in the system. Chapter Two describes the epidemiology of HIV/AIDS in women, sociocultural aspects of health, psychological and psychosocial issues with HIV positive women, and health care concerns of HIV positive

women. Chapter Three explains the phenomenological methodology utilized to study the experiences of HIV infected women in the health care system. Chapter Four presents the thematic analysis of the interviews conducted with the participants. The themes are described and illustrated with quotations from the participants' interviews. Chapter Five discusses the themes from the current research in relation to other relevant literature, as well as implications for health care and future research.

CHAPTER TWO

LITERATURE REVIEW

Women have become the fastest growing group of human immunodeficiency virus (HIV) infected people, (Buckingham and Rehm, 1987; Campbell, 1990; Ide et al., 1992; Centers for Disease Control, 1992) which forecasts the increasing numbers of women who will die from acquired immune deficiency syndrome (AIDS). The general focus of this present research is on this unique group of women. Specifically, this research focuses on their experiences with the health care system. In this chapter, the literature on the following topics is reviewed: epidemiology of HIV/AIDS in women, clinical course of HIV/AIDS in women, sociocultural aspects of health, and the psychosocial aspects of women's health.

Epidemiology of HIV/AIDS in Women

The World Health Organization (WHO, 1990) estimates that more than 3 million women are infected with the HIV virus. AIDS has become the leading cause of death for women age 20-40 years in some of the major cities in the United States, Western Europe, and sub-Saharan Africa. Women represent 3.5% of the total number of AIDS cases in Australia, 5.2% in Canada, 11% in the United States, 12.2% in Europe, and up to 50% in Africa. The transmission of the

HIV disease differs from country to country. Fifty-five percent of European women and 52% of American women with AIDS have used injection drugs. In Canada, 62% of women with AIDS became infected through heterosexual contact. Most women with AIDS are young. Approximately 25% of women with AIDS are 20 to 29 years of age, and 84% are between 15 and 44 years of age. In the United States, minority women represent the largest segment of HIV infected women. Although African-American women and Hispanic women only represent 21% of all women in the United States, they constituted 76% of all U.S. women diagnosed with AIDS since 1981 (CDC, 1993). The target population in this research is women between the ages of 19 and 40.

Clinical Course of HIV/AIDS in Women

For men and women, much of the biological processes that accompany AIDS operates in a similar manner. HIV transmission occurs predominately through sexual activity, exchange of blood or blood products, and passage from mother to newborn. HIV penetrates the CD4 lymphocytes which are infection fighting blood cells. The attack of these CD4 cells renders them nonfunctional, which consequently, interrupts the normal signalling necessary for immune responses. This breakdown in the sequence of immune system functioning may be a primary factor in compromising the immune system which in turn results in increased susceptibility to any number of opportunistic infections

(Antoni et al., 1990).

In Canada, a person is diagnosed with AIDS when it is determined that he or she has one of more than two dozen opportunistic infections such as pneumocystis carinii pneumonia (PCP), Kaposi's sarcoma (KS), and candidiasis. In the United States, a person is diagnosed with AIDS when his or her CD4 count falls below 200 (Hultz, 1993).

There are indications that HIV disease progression may differ between men and women. In one study conducted with 24 women, fungal infections were the most common, whereas, PCP and KS occurred less in women even though they are AIDS defining illnesses (Carpenter, Mayer, Fisher, Desai, & Durand, 1989). Gynecologic symptoms, such as endometriosis, cervical cancer, and vaginal candidiasis, are often the first signs of HIV infection in women, however, these symptoms are not in the group of opportunistic infections included in the CDC criteria (Smeltzer & Whipple, 1991). Since these diseases are not recognized by the CDC, women may be misdiagnosed which can lead to insufficient health care. In addition, when these women are diagnosed with AIDS, they tend to die twice as quickly as men, and 66% will die of HIV and AIDS complications without having been diagnosed as having AIDS (Ide et al., 1992). Consequently, information from this group of women about their experiences is needed to improve their prognosis and their health care.

Sociocultural Aspects of Health Care

Sociocultural aspects of health are integral to this research. When examining HIV positive women's experiences with health care, it is crucial to examine the effects of gender, race, and class in the delivery of women's health care. It is widely accepted by the field of biomedical ethics that people's health care needs usually vary inversely with their power and privilege within society. This variance is usually described in economic terms whereby health and access to health resources are largely reliant on a person's income level (Sherwin, 1992). Poverty is a significant factor in the probability of good health. Poverty contributes to factors which have an impact on health: being poor usually means living without access to decent nutrition, housing, heat, water, clothing, and sanitation, and all of these influences may have a negative impact on health (Lewis, 1990). In addition, monetary constraints usually force the poor to seek health care only when diseases and illnesses reach an advanced state, at which point, health care may be compromised due to the progression of the sickness (Sherwin, 1992).

In our society, poverty usually affects those who are oppressed on the basis of gender, race, sexuality, class, and so on. Those who are most oppressed are prone to experience the most serious and frequent health problems and have the least access to adequate medical treatment.

Sherwin (1990) provides an explanation for this susceptibility of health problems as oppressed individuals are quite often exposed to higher levels of stress as a direct result of their oppressed nature. Severe stress may be responsible for many serious illnesses and is a complicating factor is most all diseases.

Unfortunately, women have a clear disadvantage for health care opportunities based on their gender. As Sherwin (1992) noted:

> North American society is characteristically sexist, racist, classist, homophobic, and frightened of physical or mental imperfections; we can anticipate, then, that those who are oppressed by virtue of their gender, race, class, sexual orientation, or disabilities - and especially, those who are oppressed in a number of different ways - will experience a disproportional share of illness and will often suffer reduced access to resources...The damaging connection between oppression and illness are profoundly unfair. (p. 223)

Therefore, oppressed individuals are subject to more stress, and this stress is responsible for many serious illnesses and is a complicating factor in most diseases. In our society, those who encounter oppression are also likely to experience the most severe health problems and have the least access to medical care and treatment.

Although Canada does not have the private and public health care system similar to the United States, universal health care does not preclude the problems of accessibility to health care. Although poor Canadian women are not refused treatment at hospitals and clinics, they may not be able to access health care because of travel costs, child care concerns, and lack of accessible care in rural areas. In addition, some provinces are now introducing a "user fee" in which patients are required to pay a monetary fee when utilizing hospital emergency rooms and clinics (Sherwin, 1992). Women's health care may also be compromised due to physicians' and other health care professionals' attitudes towards women with certain illnesses or diseases, such as HIV/AIDS. Therefore, in this present research, it is important to examine the women's experiences with health care professionals.

Sociocultural Aspects of Health Care with HIV Positive Women

From the known literature to date, women's lives are primarily viewed and defined based on their relationships to others; for example, a wife, mother, and/or caregiver. An AIDS diagnosis further exacerbates these role identifications. Women's sexual identities are often explained by their reproductive capacity and involvement with commercial sex (prostitution) (Carovano, 1991).

The focus on these particular identities, 'mother' and

> 'prostitute', among the many that define women, leads one easily to the hypothesis that efforts to prevent AIDS among women have been the result, not of a concern for women, but rather a concern that is primarily about protecting the health of men and children. (p. 132)

As a result, there is more public focus on prostitutes who may infect their clients with HIV and mothers who may infect their children than there is on treatment and prevention for infected women (Ide et al., 1992; Pheterson, 1990). Women's chances of becoming infected are greater than men as there are more men infected than women which increases the chance that women will have an infected sex partner (Ickovics & Rodin, 1992). In actuality, a woman sex worker is up to 18 times more likely to contract the disease from a male client than she is to give the virus to him (Ide et at., 1992; Richardson, 1988). In addition, studies conducted to investigate whether or not sex workers are indeed vectors of transmission have revealed that the incidence of the HIV virus in sex workers is minimal, if not unlikely. Furthermore, it is the sex workers who are intravenous (IV) drug users who are at risk of contracting the virus (Brock, 1989; Hampton, 1988). The Globe and Mail reported a study conducted by the federal government that took place from 1985 to 1987 in which they tested 109 sex workers for the presence of the HIV antibodies. This study of sex workers from Calgary, Edmonton, and Vancouver found

that none of these women were infected with the HIV virus (Brock, 1989). As a result, research and study on HIV positive women's health is of secondary importance to research on women as vectors of transmission through their roles as mothers or prostitutes.

North America's response to the AIDS crisis has been greatly influenced by its class structure and its profit driven economy. For example, treatments that will not profit will not be tested by drug companies, and they are unlikely to be studied and researched by the government. This is made problematic for women, especially IV drug using women and single mothers, as they have limited incomes. Drug companies can not make a profit on a drug if the people who require access to it are too poor to buy the medication (Christensen, 1990). In addition, women only comprise 7% to 8% of people in clinical drug trials. Women were not involved in testing the drugs which have been approved by the Food and Drug Administration, azidothymidine (AZT) and didioxyinosine (DDI). Consequently, the side effects and efficacy of these drugs on women can only be generalized from the men involved in the trials (Pizzi, 1992). Women need to be fully involved in drug trials to ensure that their health will benefit. In addition, the small numbers of women in drug trials perpetuates the myth that AIDS does not affect women. This sends the message to women that they are not at risk of contracting the virus. As a result, this

is an important framework for the present research as women are often excluded from critical drug research and medical studies.

AIDS and poverty have a vicious bond. As women's earnings are generally substandard to those of men, women in some countries are less likely to have health insurance, and are less likely to afford the expensive medical treatments available to fight the various illnesses related to HIV. In addition to this, it is difficult for HIV infected women, who are living in poverty and are likely the sole caregiver for their children, to access affordable child care, obtain nutritious food, and afford adequate housing to ensure that they and their children remain as healthy as possible.

HIV infected women who are living in poverty may feel financially dependent on the men in their lives and feel powerless to resist sexual demands although their health may be compromised. For example, women may put themselves at risk for HIV infection, or may risk multiple infection from an HIV positive partner. For many women, sex may be means of establishing ownership, establishing a place in a more financially stable partnership, and a means of getting money to look after herself and children which is generally short in demand (Shayne & Kaplan, 1991).

Many factors influence the health of HIV positive women and their families. Life is a struggle to survive and much of daily life is dedicated to this struggle. Metzger (1977)

describes this act of balancing roles and living life: "Each day is a tapestry, threads of broccoli, promotion, couches, children, politics, shopping, building, planting, thinking, interweaving in intimate connection with insistent cycles of birth, death, and existence" (p. 7).

It is hoped that this current research will add to the literature on HIV positive women's experiences with their health care and provide descriptions of the factors that influence their health.

Psychological and Psychosocial Issues with HIV Positive Women

AIDS is a medical disease with psychological ramifications. A host of psychosocial stresses are associated with an HIV diagnosis and illness, such as stigmatization, discrimination, loss, and isolation. Much of what is known about the psychosocial stressors and psychological experience of HIV and AIDS comes from research with White gay men (Cochran & Mays, 1991), and as such, understandings pertaining to women's experiences must be extrapolated from these findings. Findings from studies on the effects of terminal illness are also inferred to seropositive women as a result of the paucity of research on infected women.

Terminal Illness, HIV, and Stigma

The psychological distress of people with HIV and AIDS

in not unlike other terminally, or chronically ill patients. Like other terminal illnesses, HIV requires numerous significant adjustments to a person's life and lifestyle. People with chronic illnesses, such as HIV/AIDS, must rearrange their previously established routines, schedules, and lifestyles in order to adjust to the many changes which results from the disease. Because health is not likely to be stable over time and will usually deteriorate, adjustments are continuous as the person's health worsens (Corbin & Strauss, 1985).

However, there are many differences between people with HIV/AIDS and those with other terminal illnesses. Some of the differences may be a direct result of discrimination as AIDS is a severely stigmatizing illness. Sontag (1989) writes that "plague is the principal metaphor by which the AIDS epidemic is understood" (p. 44) and "plagues are invariably regarded as judgments on society" (p. 54). Social support from peers and family tend to be less likely for persons with AIDS than for patients with other diseases. In studies that have portrayed persons with AIDS in standardized vignettes, university students, physicians, and other health care professionals consistently viewed these persons with much more negativity, harshness, and avoidance than persons portrayed identically but diagnosed with leukemia. Persons with AIDS were described as being more responsible for their illness, less deserving of sympathy,

more deserving of their illness, more dangerous to others, and more deserving to die. These respondents also indicated less willingness to interact with an AIDS patient (St. Lawrence, Husfeldt, Kelly, Hood, & Smith, 1990).

Anxiety and Depression

Women experience anxiety and depression in a similar manner as others with HIV or AIDS. Anxiety manifests itself in many ways that are similar to the symptoms of AIDS: sweating, weight loss, and fatigue. When a woman experiences anxiety, the symptoms may be mistaken for AIDS-related symptoms which may feed the cycle of anxiety (Richardson, 1988). When faced with AIDS, the anxiety that is experienced is often more severe and longer lasting. This in part is a result of the fact that AIDS is a fatal disease in which there is no known cure and little is known about the long-term impact of antiviral therapy for women. Women may be hesitant to disclose their status to people who may provide support because of the fear of rejection. Women who lose their employment because of the HIV infection or an associated illness may face the stresses and anxieties of caring and providing for their children in the face of economic hardships (Sherr, 1995).

HIV/AIDS may invoke a full range of depressive symptoms, including concentration difficulties, lack of motivation, profound sadness, negative affect, and disruptions in sleeping and eating patterns (Jaccard,

Wilson, & Radecki, 1995). Depression may be more intense for women who are more socially isolated and are secretive about their diagnosis. An HIV diagnosis introduces the stressors that may stimulate a depression. Women with children may not see them grow up, some women may not have children, and women may face the possibility of multiple infection if their partner is HIV positive. Many women with AIDS experience physical manifestations of the disease which may effect their self-image, such as hair and weight loss (Sherr, 1995).

Loss

Regardless of gender, "At it's simplest AIDS is about loss. It's about the loss of one's health, vitality, sensuality, and career--and most profoundly, the letting go of the future as one had envisioned it" (Hoffman, 1991, p. 468). There are many forms of loss women are faced with when diagnosed positive for HIV. Women may experience loss of self through their own death. Women may lose meaningful objects in their lives, such as their house, neighborhood, and income. Women may also lose their vision for a shared future with their children and the onus of leaving their children in someone else's care (Richardson, 1988).

Coping

Coping has been defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or

exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). Coping with HIV may involve attempting to manage the adjustments that must be made with the disease. This is especially true as one moves from a healthy, asymptomatic state, to an increasingly deteriorating, symptomatic stage of the disease.

Three distinct patterns of coping appear to surface with HIV positive people in the attempt to adjust to the disease (Feifel, Strack, & Nagy, 1987). The first coping strategy pertains to those individuals who directly confront the disease and manage it in a direct and optimistic fashion. Acceptance and resignation comprise the second coping strategy in which the individuals have negative views of themselves and are pessimistic about the future and effects of medical treatment. The third coping style involves avoidance in which the infected person denies the existence of the disease. Previous research has invariably indicated the high incidence rate of adjustment disorders and mood disorders in HIV positive people. This is especially true of people whose health is deteriorating and are starting to show signs of AIDS related illnesses (Woo, 1988). This may show that the ability of people to cope lessens as people experience more HIV and AIDS related symptoms.

Social Support

Coping capabilities can be positively enhanced with the

presence of support systems. Support networks can shield the infected person from the negative psychological consequences and negative societal reactions. Studies have shown the existence of support to be positively related to overall well-being and health and negatively related to distress and depression in chronically ill people (Hays, Turner, & Coates, 1992; Wolf et al., 1991). There are many different forms of support that are important for HIV positive women: tangible support, such as money and child care services; emotional support, in the form of empathy and understanding; informational support, such as the availability of consultation and information about HIV/AIDS; and companionship, in which a person can rely on people for support and social stimulation. Women who do not have access to some of these forms of support may jeopardize healthy adjustment and the development of adequate coping skills (Jaccard et al., 1995). In addition, women may not seek support for themselves and their children as they may fear that if they disclose their HIV status, their children may be removed from their custody (Taylor-Brown, Williams, & Metzger, 1991).

Parenting

Women are the primary caretakers of children. HIV infected women remain the primary caretaker of their family and care for themselves only if and when the needs of their family members are met. For many women, the relationship

they have with their children is of fundamental importance (Chung & Magraw, 1992). As a result, most mothers struggle with whether they should disclose their HIV status to their young children. Creating anxieties for the children about their mothers' impending death and children's difficulty in understanding the disease, are common reasons for deciding against disclosure. Children can be a source of support for positive women by decreasing the sense of isolation and providing a motivation to remain healthy. This can assist the women in overcoming or managing their despair (Andrews, Williams, & Neil, 1993). Therefore, women with children were the focus of this current research.

Illness invariably brings about financial strain on a family (Bor, Miller, & Goldman, 1993). Economic stress is usually unavoidable with single mothers who have lost their employment due to the effects of the virus. Providing adequate nutrition, housing, and obtaining child care during medical visits can be difficult when living in poverty. Perhaps the greatest concern for mothers is finding permanent care for their children. Being the primary caregiver in a family creates anxieties around ensuring that their children are provided and cared for in their absence (Andrews et al., 1993).

Health Care Issues for HIV Positive Women

As mentioned previously, AIDS is a medical disease with

psychological implications. Consequently, it is impossible to separate these psychological issues from the health care issues. For example, HIV positive women living in poverty and caring for their children will most likely choose to look after their children's health care needs before their own. Women's health care will be further compromised as a result of the lack of finances for child care and transportation to a clinic or hospital. It is futile to look at women's health care issues without being reminded of the sociocultural aspects of health that were previously mentioned.

Health can be described as "the general condition of the body or mind with reference to soundness and vigor" (The Random House College Dictionary, 1988). Physicians' skills and knowledge are not the only aspect of health care needed to maintain a healthy well-being. The relationship between a physician and a patient, the amount of information and control a patient receives about the disease, and the freedom to have control over decisions about personal health care are some of the important aspects of health care.

Physician/Patient Relationship

Research suggests that there is a dissatisfaction with the relationship between physicians and their patients. Patients are merely seen as a cluster of presenting symptoms, and are treated as independent from the disease (Halpern, 1992). When focused solely on the patient's

physical disorder, in which the emotional aspects of the whole person are excluded, medical interventions will be ineffectual. Patients' emotional distress need to be cared for and attended to just as their physical distress. Subsequently, the importance of establishing rapport would appear to be one of the most crucial aspects of the physician/patient relationship. In addition, physician characteristics such as empathy, sensitivity, positive affect, and communicating effectively are important attributes for the well-being of a patient. Effective communication involves respect, honesty, trust, and empathy for the patient's situation. These characteristics are important when treating HIV infected women as they may not be receiving any family or social support or compassion for their circumstances. Being able to communicate with physicians sets the foundation for effective treatment with infected people (Jaccard et al., 1995).

Traditionally, relationships between physicians and their patients have had an unequal power distribution. The physicians are seen as experts in all facets of the patients' health. The physicians prescribe treatment to which the patients adhere. This prevailing model enables the patients to relinquish responsibility for their health and allows the health care providers to retain responsibility for the diagnosis and treatment of the illnesses. As a result, patients feel powerless over their

health and treatment, and they are not able to personally account for their strength in coping with their illnesses. The inherent power differential can have negative consequences. For example, physicians may make treatment decisions based on their own values rather than the values and needs of their patients (Northouse & Wortman, 1990).

Physician/Patient Partnership

The more recent trend in partnerships between physicians and patients views patients as active members of their health care. As explained by Blum (1985),

> What appears a most important factor in the physician's response is perception of the patient as an active partner...There are physicians who attempt to minimize the medical mystique and encourage patients' participation. These physicians attempt to dispel aspects of transference which are detrimental to the doctor-patient relationship and attempt to encourage patients' participation. These providers indicate that the physician's role is doing things with people and not to them. (p.413)

Studies indicate that patients who have good relationships with their physicians and feel that they are responsible for the direction of their treatment, remain healthier for a longer period of time (Roud, 1986; Solomon et al., 1987). Patients who adhered to this model view themselves as partners in the task of healing and have the

primary responsibility for recovering and remaining as healthy as possible.

Responsibility and Control

It seems that having control and being responsible for life circumstances can benefit health. Cancer patients who had an exceptionally long survival time subsequent to a terminal diagnosis, attributed their success to assuming responsibility for all aspects of their lives. They created and maintained an optimistic life style and were no longer willing to engage in activities, or be with people whom they did not care about. Patients also attributed their health to their active participation in their healing and medical treatment (Roud, 1986).

Empowerment strategies developed for cancer patients assumes that individuals understand and recognize their own personal needs better than others. As such, it is important for the individuals to have as much control over decisions and consequences that will ultimately affect their lives (Gray, Doan, & Church, 1990). It has been documented in cancer research that patients' ability to assert their health care needs to professionals is essential in maintaining personal control and independence (Fiore, 1984). Men with AIDS related PCP who lived significantly longer than expected perceived their physician to be a collaborator, felt personally responsible for their health, and believed that they could influence their own health

(Solomon et al., 1987). Additional studies with people with AIDS indicates that maintaining or regaining control over their life and/or health care through active decision making and responsibility for life and health choices enables coping and living with the disease (Kelly et al., 1993; Ragsdale, Kotarba, & Morrow, 1994). However, the participants in these studies either represent men with AIDS or a very small proportion of women (i.e., 127 men and 15 women; 22 men and 1 woman, respectively). Research examining women's beliefs about control and responsibility in pursuit of health care are certainly required.

HIV positive patients need accurate and complete information about treatment options, side effects of medications, and positive and negative consequences of medical treatments, in order to make informed decisions about their health care. This information is a plausible source of control as it allows people to act in their own best interest and regain power of their health care. In addition, physicians who ask how much and what type of information the patient requires allows the patient to have optimal control and empowerment by regulating the type and amount of information received (Gray et al., 1990). The empowerment experienced when receiving information about the disease, treatments, or HIV related issues can benefit emotional health as well. In a study with HIV positive gay men, informational support (i.e., receiving advice or

information on HIV related issues) was critical in buffering the depression associated with HIV symptoms (Hays et al., 1992). This finding offers valuable insight into the benefits of gaining information and choice for HIV positive people and may be worthwhile information for health care professionals.

Attitudes and Reaction to HIV/AIDS

Studies indicate that health care professionals fear contagion with patients and experience anxiety when working with AIDS patients (Wallack, 1989). Approximately two-thirds of survey respondents believed they were at significant risk of becoming infected with HIV even though they followed hospital infection control guidelines. In addition, more than 60% of health care professionals were sceptical of information provided by national experts on their safety working with AIDS patients. Nine percent of the health care workers felt that AIDS was God's punishment and 6% felt that gay men were deserving of the virus (Wallack, 1989). It is quite probable that the patients' health may be compromised by the practitioners who feel that they are deserving of the disease.

A survey of AIDS patients experiences with physicians indicated that 63% felt that their physician had adequate medical knowledge about the virus. Although most patients felt their physician was sympathetic to their situation, only 44% recognized that they had been given an accurate

explanation of what to anticipate during the course of the illness. Most participants reported that their physician knew that they had a lover or partner, however, only 35% indicated that the physician gave suggestions for HIV testing and safe sex (Valdiserri, Tama, & Ho, 1988). These findings suggest that health care providers can improve their communication with patients and may need to address their own positions about sexuality and HIV related stereotypes.

There may be specific issues for health care providers when working with HIV positive women. HIV positive women may initiate certain reactions from professionals during the course of treatment or health care. Several reactions have been identified, although these reactions may also be present when working with infected men (Macks, 1988). 1.) Health care professionals may deny the fact that a woman is HIV positive. This denial may protect certain providers from their personal feelings of vulnerability by believing that it is a disease that only affects gay men. 2.) Practitioners may be uncomfortable with discussing sex, sexuality, and sexual behavior with HIV positive women. If practitioners have not had much experiences with infected people, they may project their own fears or values on the clients and their sexual behaviors. 3). Health care providers may feel frustrated and helpless when attempting to locate adequate resources, such as housing and food, for

HIV positive women and their families. Their impoverishment, experiences of discrimination, and limited resources are aggravated by the HIV diagnosis. 4). It is not uncommon for practitioners to feel inadequate when working with HIV positive people. These feelings of inadequacy may indicate feelings of helplessness, powerlessness, and fear when working with these clients. When working with HIV positive clients, practitioners must be willing to examine their own reactions and feeling toward this population of people in order to provide the best care possible.

Conclusion

The research literature suggests that HIV positive women have unique and specific experiences related to the infection. For example, sociocultural components intensify the experiences of being HIV positive. Women develop unique infections and the course of the illness may be experienced differently for women than men. Research with cancer patients and HIV infected men indicate that there are positive consequences to controlling aspects of personal health care and involvement in active decision making for personal health care empowers individuals. However, there is no known research which has examined women's experiences with health care. Past findings have included a few women in a sample made up of largely men participants. It is impossible to extrapolate these findings to women because of

the different medical, sociocultural, and psychosocial aspects of women's health. As a result, this current research attempts to describe the unique experiences of HIV positive women seeking health care. It is believed that this research will add to the paucity of literature on the present phenomenon.

CHAPTER THREE

METHODOLOGY

The Question

The purpose of this research was to explore the experiences of HIV positive women with respect to their health care. With this in mind, various research methods were examined to determine the most effective means of investigating these experiences. With natural science, phenomena are studied and decontexualized which may result in lost meaning for the sake of scientific objectivity (Osborne, 1990). Natural science studies of HIV positive women and health care objectify this phenomenon and eliminate the human experience inherent in these women's lives. Phenomenological methodology emphasizes meaning and understanding of an individual's experience with a certain phenomenon.

> Qualitative researchers direct their attention to human realities as opposed to the concrete realities of objects. The distinctive valuing of and respect for people in qualitative research do not allow for their objectification as featured in quantitative research. People are thus centered in qualitative research in recognition that reality is constituted in human perspectives. (Boyd, 1993, p. 79)

Wertz (1984) outlines three phenomenologically-oriented

approaches to psychological research: the comprehensive theoretical, the phenomenal, and the reflective empirical. The reflective empirical approach was used in this current research as this approach is interpretive and goes beyond the phenomenal approach by utilizing the researcher's ability to reflect on the data. This approach was chosen as it attempts to uncover the meaning of the phenomenon.

Phenomenological research explores and reflects human experience in the way in which it is uniquely and inherently encountered. As Boyd (1993) noted:

> One is tied to the world in a perspective created by being bodily situated in the world in a particular way. Because human realities are contingent on one's turn of attention to the world in a perspective that comes into being by that turn, they are always subjective in nature. (p. 85)

Qualitative researchers acknowledge that people construct their own meaning in relation to the world in which they live. As a result, phenomenological methodology uses personal descriptions of how the phenomenon under investigation has impacted individuals and may therefore provide a greater, and more complete, understanding of HIV positive women's experiences with their health care. As this research was being conducted to produce a complete and rich depiction of women's experiences with health care, it was felt that the phenomenological methodology would be the

most suitable method.

Presuppositions

Phenomenology recognizes the presence of the researcher in the formulation of the question, the determination of what are the data, the collection of that data, and the subsequent interpretation (Osborne, 1990). As experimental designs can eliminate and avoid such influences through the design of the research, phenomenologists attempt to articulate their predispositions and biases through a process of bracketing by putting aside their presuppositions as best they can. As a result, this new awareness allows the researcher's biases to be suspended and allows for a fresh immersement in the experiences of the participants (Wertz, 1984). The following is my attempt to bracket my predispositions.

Prior to moving to this present location to do graduate work, I had been involved in the AIDS Network in an Eastern province for 4 years. Before my involvement at the Network, I first became interested in HIV/AIDS related work when I had the chance to listen to a retired priest speak about his experiences living with AIDS, and as a result of this diagnosis, how he was ex-communicated from the priesthood. This was in the late 1980's, and he was one of the first people to speak out in our small city. I felt that this act of sharing was very courageous on his behalf as he had many strikes against him. He contracted the virus through sexual

activities which goes against such celibate vows.

As this man shared his experiences, I was moved at his openness in sharing his life story and the freedom he seemed to feel by allowing his true self to be shown to those around him. The freedom seemed more sweet and victorious knowing that he spent much of his life denying his sexuality from the world. Yet he learned what I believe most have not. At the end of his life, he was able to freely open himself to the experiences of the world and was known by others for the person he truly was in this life. There was no doubting the character of this man who stood and spoke about his life with authority and sensitivity. I continue to hold this experience close and take from it the importance of being known for who I am and the difficulty and fear which resides inside wondering if I too may be ex-communicated from the people with whom I am most close. From that day forward I have been involved in different aspects of the provincial AIDS Network and since moving to Alberta, have involved myself with HIV positive people through counselling work and graduate research.

Of course, reading literature on HIV/AIDS and women's health has caused me to hold certain beliefs. Since the early part of this decade, there have been shifts as to which "population" of people is thought to be at "risk" of contracting the disease. Personally, the fact that the growth of HIV/AIDS cases among women are outpacing men by

about 50% indicates the importance and need of HIV/AIDS research in relation to the virus's direct impact and involvement with women. As the incidence of HIV and AIDS is rising in women, this signifies that as time goes on, more and more women will be entering the health care system for medical and emotional treatment. However, men have predominately served in studies designed to increase our understanding of the epidemiology and possible treatment of the disease, and as a result, it is presumptuous to assume that these research findings will apply to and benefit HIV positive women. As a result, I have presuppositions about the health care available for HIV positive women. It is my position that HIV positive women's health hangs in a precarious balance as the health care system is only now recognizing the unique needs and health concerns of HIV positive women. It is for these reasons that I have a desire to contribute to the sparse literature on HIV positive women and their health care.

Participants

The purpose of this research was to describe the experiences of HIV positive women in the health care system through the use of comprehensive yet open-ended interviews. As a result, HIV positive women were sought who had experienced the phenomenon and could provide rich and salient descriptions of this particular phenomenon being studied. Most importantly, participants had to agree to

wrestle with verbalizing their experiences in the health care system.

Through a local organization, the researcher had been given a name of a woman who would be able to help acquire the permission of interested HIV positive women to be involved in the project. Through this contact, the researcher was put in touch with an HIV positive woman who in turn contacted and obtained the permission of four other women who were willing to be approached by the researcher. These women were contacted by phone to determine if they were willing to share their experiences and illuminate the phenomenon under investigation. It was perceived that these women were able to articulate their personal narratives for the purpose of this research.

There were five participants who ranged in age from 19 to 36 years. All of the women had children whose ages ranged from three months to 19 years. At the time of the interviews, two of the women were working in HIV/AIDS related employment, one was a university student, one had chronic illnesses and was unable to work, and one woman was home caring for her three children. Four of the women were single and one woman was married. Two of the women were divorced and the husbands of two women had died of AIDS-related illnesses. The women contracted the HIV virus through various means. Three of the women believe they contracted the virus through heterosexual intercourse, one

believes she was infected through intravenous drug use, and one is not certain if she was infected through sexual intercourse or a blood transfusion. The length of time the women had known they were HIV infected ranged from between 2 and 6 years, with an average time of 4 years.

There is much variation in the number of participants used in phenomenological research studies. Generally, the researcher utilizes as many participants as needed to illuminate the phenomenon (Wertz, 1984). Based on the interviews with these five women, it was believed that the data collected was sufficient in illustrating the essential aspects of this phenomenon, and as a result, additional women were not sought to participate.

Procedure

When each participant was contacted, she was informed about the purpose of the research, and the time commitment required for the study. If she was interested in the research, the initial interview was arranged. Each participant was involved in a lengthy individual interview which took place in her home. The interview was open ended and as minimally structured as possible to allow the participants to present their experiences as inherently and freely as possible. This format was used as it avoided both directing the participants' thoughts and asking questions which might have supported the researcher's own biases.

Prior to the actual interview, time was spent going

over the purpose of the interview and the aim of the study was discussed in more detail (see Appendix A). The researcher shared her background with the participants and answered any questions they had about the researcher or the study itself. In addition, informed consent, confidentiality, and the participants' right to withdraw from the study were also discussed at this time. These materials are included in the appendices. Each participant was given a consent form (see Appendix B). Ethical approval had been obtained from the researcher's institution for the study.

Care was taken to establish rapport with the participants as it is one of the most important considerations in phenomenological research. Rapport and an atmosphere of mutual trust and respect is needed to allow the participants to provide genuine descriptions of their experiences (Osborne, 1990). In such an environment, the participant feels free to communicate the richness of her experience.

The initial interview began by stating: "Tell me about your experiences as an HIV positive woman in the health care system". The researcher followed the dialogue of the participants and requested clarification or elaboration when necessary. Additional questions were utilized as probes to prompt the participants when it appeared that they had exhausted a certain aspect of their experience (see Appendix

C). Initial interviews were between 60 and 90 minutes in length. All interviews were tape recorded with the permission of the participants and transcribed by the researcher. The second phase interview involved taking the analyses and themes back to the participants to ensure the interpretations were true to their experiences. This served to validate the analyses by allowing the participants to concur with or refute the researcher's interpretation.

Data Analysis

The goal of phenomenological research is to reveal and unravel the structure and interrelationships that are obtained in the phenomenon under investigation (Polkinghorne, 1983). More specifically, the purpose of this research is to glean from the interviews a description of the integral qualities of the experiences of HIV positive women in relation to their health care. The procedural steps utilized in this research can be outlined as follows.

1. Each of the participant's protocol, or written transcript, was read and reread in order to acquire a feeling for and to become absorbed in the descriptions of the experiences of the women.

2. Phrases or sentences were extracted from the protocol that directly pertained to the women's experiences with health care. This procedure is known as "extracting significant statements" (Colaizzi, 1978, p. 59). Repetitions and statements which refer to the same aspect of

the phenomenon were omitted.

3. Establishing meaning from the extracted sentences or phrases, or "formulating meanings" (Colaizzi, 1978, p. 59) was accomplished through transforming the phrases, or paraphrasing, as they appear in the protocol into the words of the researcher. The meaning was extracted from the phrase or statement and the researcher was left with meaningful or significant statements which reflected the essential point of each of the original statements.

> This is a precarious leap because, while moving beyond the protocol statements, the meanings he (i.e., the researcher) arrives at and formulates should never sever all connections with the original protocols; his formulations must discover and illuminate those meanings hidden in the various contexts and horizons of the investigated phenomenon which are announced in the original protocol. (Colaizzi, 1978, p. 59)

This allows the researcher to move beyond the women's statements and discover the latent meanings in their descriptions of their experiences in the health care system.

4. Proceeding to move beyond the meaning of the paraphrases, themes surfaced which captured the essence of the particular excerpt. These themes were recorded beside the paraphrases and subsequent significant statement. This process is illustrated in Table 1. This procedure of extracting significant statements, paraphrasing, and

creating themes was repeated for each of the five women and represents a within person's analysis.

5. At this point, repetitions and irrelevant descriptions which were initially included were eliminated. The statements, paraphrases, and themes for all five women were pooled together and sorted into clusters of themes. These clusters were given a name and formed the first order themes. These first order themes were in turn grouped or clustered together and formed second order themes. This pooling and clustering of the themes of the five women represents a between persons analysis (Table 2 & 3).

6. The clusters of themes were referred back to the original protocols to validate the meanings of the themes, the clustering of the themes, and the clustering of the second order themes. This was achieved by enquiring whether there was anything in the protocol which was not accounted for in the themes, or whether the themes themselves implied a certain meaning which was not present in the protocol itself. Exceptions and discrepancies were noted and compared to the thematic structure to examine whether they fit or did not fit.

7. The final validating step was achieved by returning to each participant and presenting to her the final thematic structure. This was necessary in order to verify how the results of the analysis compared to her experiences. If necessary, any new data or adjustments were discussed and

changes or additions were made to the existing thematic structure. The participants responded very positively to the analysis and felt that it was an accurate representation of their experiences. Some of the women seemed surprised at the thoroughness of the analysis and the manner in which their complex experiences were reported in such a succinct yet complete manner.

Chapter Four presents a narrative synthesis of the final thematic structure punctuated with salient quotations from the original protocols used to illustrate the inherent meanings of the themes. This thematic analysis is considered to illuminate the experiences of HIV positive women with respect to their health care as described by the five participants.

CHAPTER FOUR

RESULTS

This chapter presents the results of the women's descriptions of the phenomenon of being HIV positive in the health care system. The themes which will be discussed surfaced as a result of the question "Tell me about your experiences as an HIV positive woman in the health care system?". While each interview was unique to the particular participant, the purpose was to describe some common experiences among the five women while recognizing the distinct and individual experiences of each woman.

A narrative synthesis of the final thematic structure is presented. The phases of this analysis, from the protocol analysis to the final thematic structure, is presented in Tables 1, 2, & 3. The following themes have been identified as indicators of women's experiences with health care.

Nature of Health Care

a) Stigma of HIV impacts treatment in hospital
b) Healing thwarted by health care professionals attitudes and actions
c) Unwilling disclosure of HIV status in hospital
d) Accessibility of health care
e) Need for compassionate medical care
f) Healing qualities in physicians

Importance of Support and Emotional Health

a) Common Ground: Importance of validating and normalizing experiences

b) Caring for emotional self

c) Family Impact

Wilful Living: Self-Determination

a) Mind-body relationship

b) Self-direction and personal responsibility

c) Active role in health care

d) Reactions in the face of death

Explication of Themes

Medical care is an emerging theme that addresses the issue of the healing powers of physicians and the subsequent medical care. Emotional care addresses the importance of caring for the emotional aspects of their-selves and the impact that emotional health has on physical health. Wilful living involves the sense of direction and control the women have over their lives and how this control impacts their health and outlook on life.

Nature of Health Care

Many women spoke about their experiences with physicians and how these experiences impacted their lives. For instance, most women have had negative experiences in the hospital with what they felt to be ignorant hospital staff. As a result, they were angered by the differential

treatment they received in the hospital. In addition, the accessibility of health care, the need for a more holistic view of patients, and some healing qualities of physicians were discussed. Overall, the women's descriptions had a disapproving tone when discussing physicians and medical care. The participants described various experiences with health care professionals that they believed were not helpful for their health. As a probable result of this, all of the participants were aware of specific qualities they found useful and helpful in physicians and specific qualities they looked for when selecting a physician.

Stigma of HIV Impacts Treatment in Hospital. Some participants experienced anger and frustration during hospitalization as a result of differential and atypical treatment. One participant, Cindy, describes her experience of being in the hospital and feeling that she is being treated differently than the other patients because of her HIV infection.

> When I went to have a shower I'd have to carry all my laundry all the way back instead of leaving it with the rest, I had to bring it all back and they had to bag it up separately and put these red tags on it...so it doesn't feel great...to know that you're being treated so differently and everybody's afraid of you.

Cindy also describes the experience of having different visitor's rules for her and her newborn than HIV negative

mothers.

> But I have this big huge sign on my door that tells all the precautions everybody has to take before they enter the room, and that's completely unnecessary when you're coming in to visit a little baby and nobody else needs to wear gloves or you know, gowns and stuff, so why would anybody else have to do that to come and visit my baby, it doesn't make sense.

In addition, the women feel that certain hospital procedures seemed to be a result of fear and a lack of knowledge on the part of hospital staff. Cindy describes how the janitorial staff was curious as to why they had to bleach her room every day and recounts the impact it had on her.

> I had a cleaning lady come in because she had to, she bleached everything down and everyday she came in and bleached everything down and she asked me what was wrong with me, why did she have to do this (laughs), a cleaning lady...it makes me feel a little unclean...it's nice to protect myself around here (i.e., home), but that's to protect me from stuff other people bring in and stuff that comes from everywhere, just germs and preparing food and stuff so, in a hospital where it's pretty clean and sterile I think it's feeling like they are just protecting themselves from me.

Jane was resentful that she was not permitted to care for her second newborn in the hospital in the same manner that she cared for her first newborn because of her HIV status.

> (Not being allowed to go into the nursery was) hard because I could stand beside and watch her sleep through the glass, but I mean when I had my first daughter I held her the whole time and I slept with her in bed with me the first night and she nursed right away and everything and I really liked holding her and everything and I wanted to do the same thing with this one, it just made me mad and I still get mad thinking about it.

Healing Thwarted by Health Care Professionals' Attitudes and Actions. The participants have experienced health care professionals to be lacking in knowledge and unhelpful about HIV related issues. As a result, this can compromise the health care that the women receive and can make healing difficult when they are given inadequate and improper information. Bonnie had received inaccurate information after her HIV diagnosis.

> The only thing my family doctor when I went to see her told me was that you can't ever have sex any more and she hands me a pamphlet which really didn't say a lot...and that's all she knew.

Some health care professionals may still believe that

HIV/AIDS is a man's disease. Maggie describes her experiences with an HIV clinic and illustrates how the clinic is not prepared for HIV positive women.

> And as a woman, they are not definitely not prepared, every fucking time I go there (i.e., clinic) I just, the nurse comes in, the researcher comes in and does the stuff, the nurse comes in and does her stuff, and then the doctor comes and you have to undress and get on the gown, well there is never a gown, never, there is a pair of pajama bottoms every time and every time I say "wait, don't leave the room yet, let me check, no, there's no gown, I mean, it's like they fill up the cupboards with pajama bottoms.

Cindy describes her experience of fighting with her physician over a procedure she did not want but her physician would not listen and could only seem to hear and attend to his own opinions and preferences.

> And as soon as he (i.e., physician) found out I was positive he told me that "we are going to be doing a tubal ligation as soon as this baby is born 'cause you're not having any more". I just...well, I don't want to do that. I was wanting my husband, he was considering having a vasectomy, that's not a surgical procedure, it is but it's minor, outpatient kind of stuff. I didn't want to be under anaesthetic, and go and have surgery which being positive you are always a

> little weary of surgery because it can lead to complications and infections and so on, the less involvement the better. So, that was our decision, and so then I went in to see him and he told me he was going to do this (i.e., tubal ligation), there wasn't a question. He didn't say, do we want to do this, he just said "No". So I switched doctors.

Jane stated that health care professionals working with HIV positive people need to be educated about certain facts. She believes that some physicians' unfair reactions and personal biases towards her may interfere with her well-being in the hospital.

> I think that some sort of course should be offered or made available so they know how to treat people with HIV, you know. Once that woman (i.e., nurse) even suspected that I had HIV, she just treated me terribly, you know, they (i.e., patients) don't need that on top of whatever is going on at the time, you know.

Dentists are also a concern for the HIV positive women. Cindy recognizes the importance of dental health but feels that it is obstructed by fearful dentists.

> Dental health is important for someone who's positive and that's another thing that is so frustrating because I'd like to be able to have a dentist here but there has been some approached and they're not willing to accept that, there are some that say "technically we

have to but if you asked me and I give you an honest answer then no, I'd rather you don't refer them here". Deborah's experiences with dental health also have not been positive.

> I had an incident happen once where I had some dental work done on my teeth, and the dental assistant...was just freaked (about her HIV status), totally freaked out by this and...so ignorant health care workers are not very useful.

Unwilling Disclosure of HIV Status in Hospital. Participants who have been in the hospital have felt that their choice around disclosing their HIV status is taken away in the hospital as blood precautions signs are put on patients' doors. These signs may inadvertently inform visitors as to their HIV status. Deborah describes her experience with the blood precautions sign on the door of her hospital room.

> And one of their practices at (Hospital) is to put a blood precautions sign outside your door and it's this yellow sign that whoever's in there you have to take blood precautions with and I didn't find that very useful. I had people come to visit me who didn't know my (HIV) status who were health care workers and they knew what it meant, it didn't take much for them to figure out why that sign was up there. So that wasn't very useful either.

Cindy has had a similar experience in the hospital.

> Plus you know visitors that don't know, you have family and friends that you haven't told and they don't need to know, they don't need to find out that way, or you don't need the embarrassment in front of everybody answering questions, "Why is this (sign on door) up there?".

Accessibility of Health Care. Accessing medical support and information is sometimes difficult for the participants. Lack of accessible medical care can create fear and frustrations. Cindy describes the fear she felt when there was no medical support available during a crisis situation.

> But after hours, there is nobody to call, nobody. I've tried, I tried, my kids had chicken pox and they knew that that virus could trigger shingles in me so, and I didn't know if it was, if my immune system was strong enough...or if I should be near them. And I tried calling my doctor...she wasn't on call, some other doctor was and he didn't have a clue, and I called the clinic and they weren't open, and I called 1-800 numbers and they were all shut down for the week-end. And there was nobody to call...so I was terrified and I was crying...It's so frustrating, it's really kind of scary 'cause some people will tell you, well you'll have to wait until tomorrow.

Some women find it difficult to get the needed information about their health from the physicians. Bonnie talks about not getting answers and being "passed" from physician to physician.

> When I asked the HIV doctor how this affected my diabetes, what is it going to do, "I don't know, ask the diabetic doctor", and when I asked the diabetic doctor, same thing, "Ask the HIV doctor" and I'm sitting there going "Help me do this".

Cindy is bewildered by the lack of information given by HIV clinics, and as a result, she needs to advocate for herself and obtain the information herself.

> Even when I go to the (Clinic), and they're an HIV clinic, right, and I've been going there since 1989 and I didn't know until last year that I had a higher risk for cervical cancer and I should have pap smears every 6 months, I didn't know that. How could I be a woman going there, this clinic, and not being told. It's sort of like you have to ask the questions, and if you don't ask the right ones you don't find out, there's nothing that they tell you. So that's another case where I had to do a whole bunch of finding out for myself...It seems like we are teaching everybody else, we have to learn so much and we have to be doctors and we have to be our own researchers and stuff.

Maggie describes her experience of trying to get

information and feels that the physician responded to her in a condescending manner.

> It's just so damned patronizing kind of thing, that you are not an intelligent enough human being to be able to handle it (i.e., information), or you are not emotionally stable enough to handle this.

She also discusses the paradoxical nature of access. Services are freely accessible only if the women have the resources available, such as money and child care, to access them.

> So when you use the word "access" it means it's available if you have the resources and it may not just be money, it may be that you have a babysitter to go while you get medical treatment done, that if I have to go to the hospital that I would have some child care provided, you know, that type of thing.

Deborah also stated that she can only access the medical support that she needs if she has child care available.

> If I know that my kids are looked after, I am more likely to get help that I need sooner. One of the biggest barriers to me accessing health care at all is who's going to look after the kids.

<u>Need for Compassionate Medical Care</u>. Some participants felt that their physicians do not see them as whole persons because the physicians do not know anything about their lives, families, or responsibilities. These women also want

their physicians to be responsive and respectful to their emotional needs and appreciate that this medical disease has psychological ramifications. Deborah speaks about the lack of holistic health care.

> There's this sort of holistic response to health care that doesn't exist. I don't understand why none of the health care providers consider what the psychological impact must have been at home, and even the physical impact must have been like at home.

The lack of holistic care the women receive is made apparent by the inappropriate advice given by physicians as they do not know anything about the lives of their patients. These women believe that if their physicians were able to implement a more holistic treatment plan, their health would benefit as their treatment plan would be directly related to their own personal choices, responsibilities, and life-styles. Maggie talks about inappropriate advice given by her physician.

> How do you tell a woman, you just go home and take care of yourself, get lots of rest. Usually the doctor tells me, "Well, Maggie, you just sleep when you need to sleep", "Oh, okay, are you going to tell my kids that (laughs), oh, that's wonderful, I can sleep whenever I want"...They (physicians) don't know anything about your life, it's that holistic view of what's, what this person has, what resources this

person has to fall back on.

Having an emotionally supportive physician is also important for the participants. This is especially important when in the hospital as emotional needs are not always addressed during hospital stays. Physicians' reactions at the time of diagnosis can be helpful or detrimental. The importance of having a supportive physician at this particularly critical time is crucial. Cindy speaks to this importance.

> Because she seemed to listen to me...she doesn't treat me any differently which is kind of nice. It's like she has always been very nice and when my husband was sick in the hospital she came in to visit him and she helped me out with that, she talked to me in people talk instead of doctor talk, and was a comfort. She's just like the kind of doctor that I like in that she, you actually feel that she cares for you, instead of just another number or something.

Cindy continues to express how her emotional needs were not being addressed in the hospital.

> They (i.e., hospital) seem...to be less educated and tend to go overboard...in a hospital it's more anonymous and so they kind of treat you a little differently like you're just a person and we don't really care too much about your feelings and what might be going on. It's like somebody else can take care of

> that so, they don't seem too compassionate as far as how things they might be doing would affect me.

The women expressed the importance of having a supportive physician at the time of their diagnosis. To be given this diagnosis is itself very difficult and having an unsympathetic physician makes it more stressful. Jane remembers when she was diagnosed.

> (At the time of diagnosis) I needed to know that I would be okay...I just didn't expect nothing (from the physician), and that's what I got and I was really surprised. I know doctors aren't supposed to be psychologists or you know, but I just wanted some reassurance, but I never got anything from (physician). Like nothing.

However, Deborah found support from her physician when she was diagnosed.

> My GP was really helpful, my GP was very... supportive, and so (physician) was very comforting because (physician) knew how much of a shock it was.

Healing Qualities in Physicians. The participants had certain qualities and characteristics that they felt were important for health care professionals to possess. These desired qualities were not exclusive to having substantial knowledge in HIV/AIDS research, but qualities such as availability, trustworthiness, respectfulness, and ability to communicate effectively. Jane speaks about the

importance of a physician to communicate in a respectful manner.

> Somebody (i.e., physician) who can...who talk to people...I think health care people should be able to speak to their patients like one-on-one and not say something and then have the patient ask "Well, what does that mean?" and the doctor say "Oh, you don't need to know" or "This is just the way it is".

Cindy appreciates that her physician makes herself available.

> She says "Come whenever you feel you need to and I'll answer your questions" and she's available on the phone too. I can always call her and talk to her in person which you're not always able to do with doctors.

Maggie also appreciates the availability of her physician.

> I've gone in there (i.e., physician's office) and I've just needed to talk to him and he's spent like an hour sitting down and talking and one time the cleaners were there at 5 o'clock at night and I was still sitting there, so it's good.

It is important for these women to have physicians who are willing to find information about HIV related issues to be of greater assistance. Bonnie talks about finding a physician who was willing to research into the area of her need.

> I had finally found...a doctor who...dealt with people

> who had lost babies and had died and deal with the grief and that, and she went out and found information for me because she didn't know anything much about it either, she hadn't had to deal with it, but at least she was willing to go out and try to find something.

Deborah discusses the importance of having a physician who treats her with respect and equality.

> I was totally treated like a colleague, I was treated like someone who had a brain...That's the way our (i.e., she and physician's) relationship is, our relationship is, our relationship is not one of doctor/patient, it's one of partners in my health care, which is the way I think it should be.

Importance of Support and Emotional Health

The participants acknowledged the importance of maintaining or achieving good emotional health. This can be achieved through various means, such as, psychotherapy, support groups, and talking with family and friends. For the single mothers with young children, their health may be jeopardized if they do not feel supported in caring for their children. If they do not receive assistance with their children when they are experiencing ill health, these mothers are less apt to seek the much needed health care.

Common Ground: Importance of Validating and Normalizing Experiences. All but one of the participants stated that it

was important to be with others who have had similar experiences or who are knowledgable about HIV related issues to validate and normalize their experiences. Bonnie describes the relief she feels when she is able to validate her experiences with others.

> Knowing there is someone out there. That you're not going crazy. I deal with that a lot with (Staff) at the hospital and I go, "Is this normal! Why am I doing this?" and even when I know it's normal, it's nice just to have that verification of that, just to hear someone else say that it's okay, you're supposed to be doing that and it's okay to do it.

For Cindy, the support group with whom she associates allows her to validate her experiences as well as learn new information about new treatments, research, and alternative therapies.

> We tell about new treatments and stuff they heard of and someone's in a study group and somebody's using these herbs or that herb, and what works and what doesn't and how they feel, and just even sharing symptoms and what's normal and what's not is nice to know. When you are all by yourself, it's not a good idea, it's just too strained.

However, not everybody experiences a support group as a source of support or validation. Jane would leave the meetings feeling more depressed than when she arrived.

> It (i.e., support group) seemed like a competition of who was going to die quicker, that sounds really bad but that's kind of what it was like and so I think I went one more time after that but then I couldn't be bothered. It was more depressing than, I thought it was supposed to make you feel a little better you know. I'm not saying, I realize it's a place to vent how you feel and stuff but I came away from there feeling so depressed and thinking, great, is this what's going to happen to me in a couple of years rather than feeling better, so I just couldn't be bothered with it.

Caring For Emotional Health. The women described many different ways of caring for their emotional well-being. Like Maggie, most women expressed the need for support from family and friends.

> I don't use professional counsellors or therapists, I just use all my family and friends.

However, Deborah has found psychotherapy to be beneficial.

> I have a therapist that I started seeing when I was going through some pretty rocky times with my ex before we split up...and then I was diagnosed so I continued to see her since then, so I am very lucky that I have that long term therapeutic relationship.

Some women are learning new ways of taking care of themselves. Cindy is learning to reduce her anxiety and relieve stress and appreciates that her emotional well-being

is now an important part of her life.

> I've actually been doing a lot of work for myself with just spiritual growth and nourishing inside, even eating right and working out...people create a lot of their own stresses, you know...I haven't been as stressed out and I've been learning some new ways to deal with things, just even knowing that life is going to be a lot of pain makes it not so painful, and just keeping in tune with what's going on in my body...and working out and doing stuff that relaxes you, just trying to keep on top of it...Since I've been working hard at it (i.e., emotional health)...it becomes less work...it's like a way of life and a way of living.

Family Impact. The single mothers with young children recognized that their health may suffer due to inadequate child care support. As a result, they will not seek health care if they are not assured that their children are looked after. These women also expressed that their health care needs are secondary to the needs of their children. Maggie explains the importance of having child care for her children and how her children's needs are primary to her needs.

> I mean, if I was ever hospitalized...it would make a hell of a difference (knowing the children were cared for)...for sure, I mean, I can't see, no person can get well when their main concern is somebody outside

> themselves...People will tell you, "Oh, well, you should think of yourself first", well that's fine and dandy to say that but my responsibility is still to my kids and also my responsibility, part of what I choose, was also to have kids.

Deborah speaks about her health suffering due to the absence of child care.

> So the impact of health, if you don't have some security in knowing that your kids are going to be looked after, and that they are not going to be taken away from you because you are going to be seen as an incompetent mother, if you don't have that kind of peace of mind, you are not going to seek health care, you're just not...I am having to cope with two other human beings' needs other than my own and my health is bound to suffer as a result.

She also acknowledges that it is difficult to ask for help with her children because it may be seen as an admission that she cannot cope.

> Because it is really hard for me to ask for help, part of it is a fear that my kids will be taken away from me because I am a single parent...that somehow that's going to be an admission that I can't cope...And granted I have a lot of responsibility there to start asking for the help myself when I am sick, but it is really difficult to do.

Wilful Living: Self-Determination

The participants acknowledged the presence of a relationship between their emotional health and their physical health. The women expressed that if they are emotionally healthy, their physical health will likely benefit. As a result, a sense of control is attained or regained over the illness, and feelings of personal power are maintained in their lives. This is one of many ways the participants gain or maintain control in their lives as they seek to successfully cope with the disease. The participants expressed experiencing personal responsibility by being accountable for their own reactions and decisions and not concerning themselves with the reactions of other people. They also maintained control over their lives by taking an active role in their health care decisions. Despite the unanimous importance for all five participants to have an active role in their health care, there is no uniformity in their acceptance of the disease. This is evident from their descriptions as their reactions to the disease seemed to indicate that they are at different stages of acceptance.

Mind-Body Relationship. All of the participants believe that there is an important connection between the mind and the body. Many believe that emotional health can positively influence physical health, and as a result, they are using their psychological skills to help their physical

process. Jane speaks about maintaining an optimistic attitude.

> I truly believe that if you think you're going to be sick, you are, and if you think about being well, that, that does a lot more for you than thinking about being not well. I think a positive attitude is about the best thing you can have.

Cindy expresses how her emotional health can positively impact her physical health.

> I haven't had any colds or infections or anything for months since I started becoming more conscious of what's been going on (i.e., emotionally).

Maggie explains the importance of concentrating on her health.

> If you're not well in your life, why would you be stimulated to be well in your body, you know. If I'm not happy, if I'm upset about my kids, if I'm upset about anything, my community, if something's affecting me at all, uhm...I'm obviously going to be stressed out over it or tense over it or thinking about it and not thinking about being well, and not that I have to think about being well, but I think it's just going to distract and the one thing that stress does to you is eat your immune system.

Self-direction and Personal Responsibility. The participants expressed being personally responsible for

their reactions but not responsible for the reactions and opinions of others. Living their lives according to their own direction and focus allows them to have control and personal power. Being personally accountable for decisions and not being pulled down by other's reactions are part of welcoming personal responsibility. Maggie speaks about being accountable for what she says and not for others' reactions.

> I guess I've learned that...if somebody thinks I'm off the wall, good, fine, I don't care, I really don't. I don't worry so much about people's opinions about me and whatever, and I talk about what I need to talk about, you know,... I'm more direct and straight forward...I know that if somebody can't take that (i.e., something she said), it's okay, I realize that the other person can't deal with it, you know. I don't put it on myself that I shouldn't have said it, I realize that they couldn't deal with it.

Jane describes how she does not get pulled down by peoples' reactions to her.

> I don't care who agrees with my choices or who doesn't, that's their problem, not mine. I get to a point, it's not not caring, it's just, you can't really...give a damn about what other people think of you, otherwise that's all you worry about.

Cindy welcomes personal responsibility for her life

experiences by choosing to be accountable for her decisions.

> I have a friend who is just like that (i.e., feels sorry for himself) and he blames everything on the world and this and that and the other thing, but I just accept responsibility for what happens to me and try to make the best of it.

Taking Active Role in Health Care. The participants felt it was important to be actively involved in health care decisions and be informed consumers of medical treatment that they received. They want to be well-informed as to the advantages and disadvantages of different treatments and medicines that are prescribed. By managing health care and making choices and decisions, a sense of control and responsibility is preserved. Taking an active role in health care also includes taking an advocatory role in health care decisions to ensure personal needs and concerns are being met. Jane speaks to the importance of being actively involved in health care decisions.

> I know there are some people out there that if their doctor says this is the way it is, that's fine with them, but not for me. I like to know why they have to do things, and the risks for everything...I know what's going on, I feel like I'm in control, control for me is like really important...I mean these decisions with my health, they don't only affect me, they affect my kids, and so, I just have to stand up and do what I think is

best for me.

Bonnie also wants to be an informed consumer of medication and medical treatment.

> I'm not happy to be told, you've gotta take this, I want to know why, what it's going to do, why this as opposed to something else.

Deborah feels that the disease has ultimate control over her body, but she maintains some control by managing her health care.

> This disease takes away all of your control or power over your body...I can do all the right things and it's not going to make any difference in terms of my being able to control what happens. I have some measure of control if I take antiretrovirals, and that might control how fast the disease progresses. I can control...how well I eat...I have control over how much exercise I get that may or may not impact the progression of the disease...When I am given choice and power over my own health care, it allows me to feel like I am back in the driver's seat again...have some control over this disease and I may not have complete control over this disease, but it gives me some which is better than none.

Maggie believes it is important for health care workers to provide skills and choices so that she can take care of herself, make her own decisions, and have control over her

health care.

> Say you walk into a social worker and you say to her, uhm... "You know, like I'm really upset about this and I don't know what to do about it", and she sits you down and she talks with you and you walk away and you feel okay, but she didn't talk to you about what you could do about it, you know Like here's some other choices of places to go or people to talk to, here are some other people who have experienced the same thing, maybe you'd like to talk to them, you know. They just don't do that, it's like, "Just come back and see me next week. I'll take care of you"....Care givers (i.e., as opposed to care takers) give, they give as much as they can. They give as much information as they can, they give you as much resources as they can, they give you as many choices as they can.

For Cindy, taking an active role in health care also included advocating on her behalf.

> I actually wrote to the Canadian Dental Association and had him reprimanded because he wasn't supposed to do that (i.e., refuse to treat her and refer to other dentists)...it felt good to do something about it 'cause you feel kind of helpless...But it is better to do something about it even if it doesn't really do much, big deal he got a letter, but you have to hope that maybe it'll make it easier on other people, it may

not.

Reactions in the Face of Death. All the women are at different stages in their acceptance of the disease. The descriptions indicated that there is much variation between the women. For instance, Cindy speaks about how the disease has been an impetus for change and an opportunity for improved psychological health.

> I think this disease, you can go either way with it...you can get into a real feeling sorry for myself and you can get so stressed out it can make you sick...To accept the fact that I'm sick, but that I might live for another 15-20 years the way things are going, there are new treatments and they're extending the healthy years for a lot longer now so you just have to stay positive and don't focus on everything that's not going right 'cause everyone has problems...This HIV makes you, it sort of forces you to be this way...to be more positive and more in tune with yourself and what's going on and if you don't it can be, I don't know, it can make life worse for you.

Jane has continued to live her life just as she did before the HIV diagnosis. Perhaps her young age enables her to distance herself from the possibility of her health deteriorating. Her good health may allow for the negligence of the disease.

> For me like I'm young, eh, I'm only 19, and I'm not

> really all that concerned about my health now because I feel good and everything so, I don't really bother with anything, I don't feel there is anything specific that I need for my well-being...But for me it is easier if I keep myself busy and I don't have to think about any of it and right now I'm not sick so it's pretty easy to dismiss the whole thing (i.e., HIV status), you know.

Most women are amenable to trying alternative therapies in addition to traditional medicine. Their desire to live inspires them to try new treatments in hopes of extending their lives. Deborah explains her interest in alternative therapies.

> And I thought well it can't hurt so, and the massage therapy, I figured anything that can relieve stress has got to be good, so that was one of the reasons I tried, I'd like to try more, I'm really interested in trying out acupuncture and I've heard that my GP is doing some training in acupuncture so I want to ask her about it, I guess because my immune system is deteriorating so rapidly, I'm almost willing to try anything as long as it's one of those things where it can't hurt, as long as it can't hurt, I'm willing to try it.

Summary

The women in this study have experienced many similar aspects of being HIV positive in the health care system. The purpose of the open-ended interviews was to allow the

women to discuss issues that were central to their experiences. Despite this, each woman described experiences that were common themes to most, if not all, of the participants. Although each woman brought her unique perspective, the common structure of so many of these themes empowers this analysis.

All five participants felt that the attitudes and actions of health care providers can impede health care. The women have experienced this hindrance in different ways, for example, professionals expressing erroneous information about HIV and it's effects, professionals treating HIV infected women poorly because of their diagnosis, and professionals making assumptions about the ability and intelligence of the women to comprehend certain information.

Four of the participants find it difficult to access medical information or treatment as services are freely accessible only if the women have certain resources, such as money, transportation, and child care. The one woman who did not share in this theme acknowledged that she has not yet tried to access medical support or information.

All of the participants described certain qualities that were important in health care professionals. These included communicating in an effective, non-patronizing manner, being educated about HIV related issues, and being available to discuss concerns regardless of the time of day. In addition, the women expressed the importance that their

emotional health is cared for by health care professionals. The women experienced this in differing ways; for example, some did not have supportive physicians at the time of the HIV diagnosis, some believe that physicians' are not aware of their responsibilities (i.e., children) and are unsympathetic to their situation, while others feel that they have emotionally supportive physicians.

Four of the women believe it is important to be with people who have similar experiences and who can validate and normalize personal experiences. This also aids in maintaining their emotional health. The participants engaged in activities that they believed assisted in preserve their emotional health. Some women utilize psychotherapy, others talk to family and friends, and others are learning to care for themselves to ensure their needs are met.

All the participants who are single mothers with small children expressed that their health is secondary to that of their children's health. As a result, they indicated that their health may suffer due to inadequate child care support and they will not seek health care if they are not assured that their children are looked after.

The women conveyed that they take an active role in their health care. This is done by being an informed consumer of medication, making decisions about the direction of their treatment, and advocating on their own behalf to

ensure their health care needs are satisfied. In addition, the participants all concurred that they do not concern themselves or get pulled down by others' reactions to them and they take personal responsibility for their decisions and life choices. Participants also agreed that emotional health can influence physical health. As such, it is important to think about being healthy and to maintain an optimistic, hopeful attitude to be physically healthy.

Perhaps the theme with the greatest variation was their personal reactions to the disease. Some found it to be an impetus for positive change, while one woman continues to live her life just as she did before the HIV diagnosis.

CHAPTER FIVE

DISCUSSION

The experiences of HIV positive women in the health care system constituted the phenomenon explored in this research study. Five women agreed to participate in this investigation. From an analysis of each of the interviews, three fundamental themes emerged. These themes were "Nature of Health Care", "Importance of Support and Emotional Health", and "Wilful Living: Self-Determination". Although numerous common themes emerged in the stories and accounts of each woman, each participant provided unique and distinctive modulations of the items. The women had common experiences, which they reported, and there was commonality among the themes which emerged. These themes will be discussed in relation to current research on HIV positive women and whether the women in this present research support or disconfirm previous or related findings.

Nature of Health Care

Certainly, the stigmatizing nature of the disease may impact the quality of health care received by the participants. The women experience unhelpful attitudes on the part of physicians about HIV related issues. The women in this research who have been hospitalized have experienced anger and frustration as a result of differential treatment

in the hospitals. They felt that some of the procedures to which they were exposed were performed as a result of fear of contagion on the part of hospital staff. Perhaps the lack of knowledge and understanding found in health care professionals is most alarming because of the assumption that they are the experts on the modes of HIV transmission, infection, and treatment. This finding is consistent with the literature which indicated that health care professionals may well fear contagion with HIV infected patients (Wallack, 1989). In one study, researchers reported that two-thirds of surveyed health care respondents believed they were at significant risk of becoming infected with HIV even though they followed standard hospital infection control guidelines (Wallack, 1989). Moreover, additional research reported that health care providers consistently rated HIV positive patients as less deserving of sympathy, more responsible for their illness, and more deserving to die than patients with leukemia (St. Lawrence et al., 1990).

The five participants describe certain qualities that they either wish for or appreciate in their physicians. Some of these include the physician's availability to address the women's concerns, ability to communicate in non-condescending manner, and the ability to have an egalitarian relationship with their physicians. This desire for HIV positive women to feel respected is also seen in the

literature where effective communication is described as respect for the other person, empathy, honesty, and trust. These qualities are deemed important when working with infected women as good communication can be an important component of effective treatment (Jaccard, Wilson, Radecki, 1995).

In addition, physicians' sensitivity during difficult times is important to the women in this current research study. Some of the participants experience their physicians as compassionate and supportive while others do not experience their physicians as a source of comfort. Interestingly, similar findings were found when 34 persons with AIDS in two Boston clinics were asked what would help health care providers better care for them, most of the participants replied that more empathy and acceptance would be helpful (Longo, Spross, and Locke, 1990). Certainly, the women in this study feel they would also benefit from support and empathy from their physicians.

Also, there is a dissatisfaction about the quality of the relationship between patients and physicians. All of the participants who have accessed physicians' care feel that they are not seen as whole persons because the physicians do not know anything about their lives. This may result in fragmented health care and inappropriate advice to the women. For example, if physicians tell the women with small children to go home and sleep and rest as much as they

can, they have not taken the time to discover the women's family responsibilities and the different roles they must fulfil in their lives. Often, patients are seen simply as a cluster of symptoms that need curing, instead of people with lives and problems. However, to optimize health care, members of the medical community are now beginning to realize that physicians need to treat the whole person along with their physical symptoms (Halpern, 1992).

In addition, participants in this project prefer to have an egalitarian relationship with their physicians as opposed to the more traditional relationship in which the physicians are regarded as experts in all facets of their patients' health. This is also supported by the literature as a good relationship with a physician, one in which the patient viewed him or herself to be partners in the act of healing, was an important aspect of health care for cancer patients. These cancer patients remained healthy for a longer period of time than patients who had a traditional relationship with their physicians (Roud, 1986).

Physicians and other health care professionals also need to be sensitive to the difficulties that the participants face when accessing health care. All but one woman indicated that accessing health care is a difficult task. For the single women with small children, health care can only be accessed if they have child care available. Furthermore, child care can only be accessed by these women

if money is available to pay for the care. The one participant who did not agree that accessing health care was difficult reported that she has not yet attempted to access health care and therefore can not relate to this finding. It may be important to note that in addition, she is married and her husband contributes to the raising and caring of the children. This may make it easier for her to access health care when needed. As mentioned previously, although Canadian hospitals and clinics do not turn low income women away, it is hard to access medical support without child care, transportation, and money (Sherwin, 1992). As a result, these women are not likely to access medical support as quickly, or as often, as women and men who do not have children.

Not only is it difficult to access medical care for the five participants, but it is also difficult to access information about the disease. It is important to have accurate and complete information about medical options in order to make informed decisions about medical treatment. The importance of having access to information was also confirmed by the literature which reported that having access to information was beneficial when coping with the HIV disease and buffering depression (Hays et al., 1992; Weitz, 1989). In addition, research with HIV positive gay men described that those who were obtaining information about AIDS believed that they could get better care from

health institutions and could achieve a higher level of health as a result (Gloersen et al., 1993).

Importance of Support and Emotional Health

It is important for four of the women to be with others who have had similar experiences with HIV and who can validate and normalize their experiences. As indicated by the literature, support groups specifically oriented to women allow them to discuss issues that are more unique to women, such as concerns about disclosing the illness to their children and the caring of their children when the women become ill (Foster, Steven, & Hall, 1994). Studies have also indicated that breast cancer patients who received group therapy survived longer than those who did not participate in such groups (Spiegel, Bloom, Kraemer, & Gottheil, 1989). It has been discussed that social support may be an important factor in survival rate, and social support for those who otherwise feel isolated can improve health outcomes. In addition, a support group may provide a sense of acceptance and a place to belong and to express feelings. This support from similar others can also be empowering and can normalize the emotional distress associated with the illness (Gray, Doan, & Church, 1990; Haney, 1988; Pizzi, 1992)

The women in this current research not only find support from other infected people, but also from family and

friends. For the participants, an important component of caring for their emotional health is seeking support from understanding others. In a study designed to examine the phenomena of "doing well" in people with AIDS, experiencing support was one important aspect of coping and managing the HIV virus (Gloersen et al., 1993). Although, the majority of participants were gay men, it seems that support is an important aspect of coping with the illness regardless of gender. In fact, research with HIV positive men has found that if they perceive that they have low levels of social support, it is possible to predict that they will experience higher levels of depression (Kelly et al., 1993). Also, HIV positive men who were satisfied with their social support were less likely to show an increased level of depression one year later (Hays et al., 1992). Indeed, social support appears to act as a buffer against depression. Social support may take a unique twist with women because of specific parenting concerns. As in this present study and validated by other findings, single women with children are less likely to seek support for fear that they will be viewed as incompetent and lose custody of their children because of their HIV status (Taylor-Brown, Williams, & Metzger, 1991). As previously mentioned, low social support may result in increased depression and isolation for HIV positive women.

Also, the single women with small children in this

study recognize that their health will suffer due to inadequate child care support as they will not seek health care if they are not assured that their children are looked after. One woman in this study has an adult daughter in which accessing child care is not relevant. However, as supported by the literature, the four women with small children remain as the primary care givers in their families in which their health is secondary to their children's health (Health and Welfare Canada, 1990; Ide et al., 1992). As previously mentioned, this also impacts the accessibility of health care as the women are less likely to access medical support because of their familial responsibilities and their lack of financial resources to provide child care and transportation to the clinics.

The primary concern for most of the women in this research is finding child care for their children if they were ever to be hospitalized. Of the five participants, one woman has an adult daughter, one is married and knows her husband will care for their children, and one single woman has pre-arranged child care. The other two women do not know who will care for their children if they are hospitalized. This is one of the greatest concerns for many HIV positive women. The HIV positive women in a study by Andrews' and colleagues (1993) expressed similar feelings of anxiety in relation to their children and finding permanent child care. Even if women have pre-arranged child care,

they experienced feelings of guilt over having to leave their children, thereby removing their special motherly care that they feel they are providing.

Wilful Living: Self-Determination

The participants in this study report that emotional health can influence physical health. They believe it is important to think about being healthy and to maintain an optimistic attitude in order to uphold their physical health. Thus, the participants argue that strong emotional health will positively influence their physical health. Regarding this idea, there is a growing body of psychoneuroimmunological research whose aim is to define the relationship between mind and body for cancer and other illnesses (Gray & Doan, 1990). Although this is a newly emerging area today, a review of the late nineteenth-century literature reveals hundreds of articles which attested to the contribution of psychological factors to somatic illness (Myers & Benson, 1992). During the eighteenth and nineteenth century, physicians believed that the loss of hope and the onset of despair following a traumatic event could contribute to the onset of cancer (Kowal, 1955). More recently, LeShan (1989) has linked personality characteristics and cancer. He asserted that when cancer patients were unable to express negative emotions, they were instead agreeable, amiable, and helpful to other people. As

a result, he felt that the onset and expression of cancer was a consequence of such repressed emotions and the ignorance of true inner feelings. Therefore, it is important to examine more thoroughly and understand more clearly the complex relationship between psychological and physical health. However, it is difficult for cancer patients and AIDS patients alike to believe that they have in some way caused their illness. These patients are quite likely to experience a great deal of guilt if they accept responsibility for their illness.

In addition, in recent years, there has been a growth of research into the psychosocial influences on the progression of HIV infection (O'Leary, 1990). For instance, earlier studies reported that anxiety and hopelessness can negatively impact the immune functioning of persons with AIDS. These results suggested that less adequate psychological defenses may be associated with impaired defenses to the HIV virus and subsequent opportunistic infections (Solomon & Temoshok, 1987). In addition, other research indicated that poor coping styles and significant life stressors were predictors in the progression of AIDS (Goodkin, Fuchs, Feaster, Leeka, & Dickson Rishel, 1992).

The five women in this research do not concern themselves with others' reactions to them and have no desire to please other people. They welcome the sense of personal responsibility and empowerment and are accountable only to

themselves for their life choices and experiences. Concerning this concept, Gloersen et al. (1993) examined the phenomena of "doing well" in people with AIDS. All of their participants identified accepting to be an important concept in achieving a sense of well-being. This acceptance included knowing the self, being honest with self and others, and reevaluating life priorities. In addition, cancer patients who had an exceptionally long survival time attributed part of their success to their unwillingness to engage in activities or be with people whom they did not care about (Roud, 1986). This supports the current research as the participants seem to prioritize whom and what is important in their lives and are not affected by people who do not have an interest in their well-being.

Similar to the concept of personal responsibility, all of the participants assume an active role in their health care. They want to be responsible for making health care decisions that will affect their health, and to be informed consumers of prescribed medication. It is important for the participants to feel in control of their personal health care and be responsible for their health. Recently, this concept has been addressed by cancer researchers. Research has shown that most cancer patients are empowered by actively participating in their treatment process (Gray et al., 1990). Additional research has shown that cancer patients desire a more active role in health concerns and in

fact, they should be encouraged to assume a more active role in their care because of the positive health benefits (Northouse & Wortman, 1990). Cancer research has also shown that active participation in health care is associated with positive physical and mental health outcomes (Schulman, 1979; Roud, 1986).

Similarly, studies with persons with HIV infection indicated that "active" coping and the assertion of control were associated with improved adjustment and longer survival time than more passive, helpless coping styles (Solomon & Temoshok, 1987). Men with AIDS related PCP, who lived significantly longer than expected, perceived their physicians to be collaborators, felt personally responsible for their health, and believed they could influence their own health (Solomon et al., 1987). In addition, studies with HIV positive men indicated that taking an active role in their health care and medical decisions enabled coping and living with the disease and improved the psychological well-being and quality of life (Gloersen et al., 1993; Kelly et al., 1993; Remien, Rabkin, Williams, & Katoff, 1992).

Reactions to the HIV disease are unique for each of the participants. The reactions vary from viewing the disease as an impetus for positive change to not thinking about the disease and living life as it was before the diagnosis. Some women can maintain a sense of optimism despite their diagnosis and they face death with a new sense of

opportunity for life. This is perhaps the area in which the least amount of research has been conducted. To date, there are no published studies on how HIV positive women make sense of the disease, ascribe meaning, or react in the face of death. The little research that has been conducted with gay men indicated that the majority experienced a positive change since their diagnosis, and they viewed HIV as a catalyst for personal growth (Gloersen, 1993; Schaefer & Coleman, 1992; Schwartzberg, 1993).

Limitations of the Research

In addition to discussing the current findings of this research, it is also important to discuss the limitations of this study. The phenomenological methodology lends itself to the inherent difficulty of researcher bias. The interpretation of the interviews and the thematic analysis may be influenced by the researcher's presuppositions and biases. Through the process of self-reflection, and putting any presuppositions in written form, the researcher can be aware of such biases and attempt to minimize any influences that these may bring to the research results. In addition, the process of self-reflection can also allow the readers to be cognizant of the researcher's bias and predispositions (Osborne, 1990).

Due to the unique characteristics of the women in this research study, the themes are not generalizable to all

women with HIV. Age of the women, stage of the illness, and diverse family units may uniquely contribute to the experiences of the participants. However, because phenomenological research is not concerned with statistical generalizability, this research is considered generalizable to the extent that it resonates with other HIV positive women and they agree with the outcome of the research. Thus, if the themes of a woman's experience resonates with the experiences of other women, it is said to have empathic generalizability (Osborne, 1990).

Directions for Future Research

The generalizability of the present research findings to other HIV positive women was previously mentioned as a possible limitation to the study. As a result, in the future, it may be beneficial to conduct similar research with women of similar age, at a similar point in the progression of the disease, and with similar family units. For instance, participants could include 35-45 year old asymptomatic single women with children. These women may have unique experiences that are distinct from other women with partners and/or with no children. Streamlining the sample of women would allow for the illumination of experiences of a specific group of infected women.

In addition, it may be advantageous to examine some of the themes in more detail. This research study describes

important experiences that many of the HIV positive women shared. However, there is merit in elucidating some of these themes to bring more clarity and detail to them. For example, future research may focus more closely on the importance of the physician/patient relationship and how this relationship may impact the health care of HIV positive women. In addition, the role that children play in an HIV positive woman's health and the impact a family has on receiving and accessing health care are other important research areas.

As the sample of women in this study was relatively small, creating a survey based on this present research may be of value. A national survey based on themes described in this current research could determine the extent to which this present study was effective in describing the essence of HIV positive women's experiences in health care.

As well, in this study, the theme "Wilful Living: Self-Determination" described the personal responsibility and active role in health care that is maintained by these women. Research on HIV infected women in this area is lacking. By examining this area more closely, it may be possible to explore the implications and ramifications of retaining personal control and making decisions about the direction of personal health care.

There is also very little research on women's personal reactions to the HIV disease and how they make sense of the

virus. This present research suggests that most women may find positive meaning in their diagnosis and use it as an impetus for positive change. It may be important to further explore and understand how women arrive at this place of acceptance during the course of their HIV disease. This proposed research will not only benefit the women with their coping, but will also benefit the health care professionals with whom they intimately work.

As all of the women described experiences in which they felt discriminated against, treated unfairly, or became the recipients of erroneous information by health care professionals, it is important to examine this finding more closely. As HIV positive people are in frequent contact with physicians, nurses, and other professionals, it is necessary to research the biases and prejudices of health care professionals.

Implications for the Health Care System

This present research study has revealed several implications for the health care system by describing the experiences of the five HIV positive women who participated in this study. These implications are as follows: First, it is important for physicians, nurses, and other health care professionals to recognize that it is difficult for many HIV positive women to access health care. Many positive women have low incomes and may be the sole care providers for

their children. Thus, this restricts the possibility of accessing health care for financial and child care reasons.

Health care professionals may improve their patients' health if they have more appreciation for the context and circumstances of their patients' lives. For instance, appreciating the complexity of child care and the women's responsibilities to their families, the physicians may be able to give more appropriate medical advice and care to the women.

As this current research indicates that it is important for HIV positive women to have an active role in their health care, it is vital that health care professionals inform the women of medical choices, treatment options, and effects of medications. Women need to be fully apprised about medical aspects of the disease so they can make informed decisions as to the course of their treatment.

Perhaps one way of ensuring that women take an active role in their health care is having an egalitarian relationship between the physicians and patients. As two women said, "Our relationship is not one of doctor/patient, it's one of partners in my health care, which is the way I think it should be", and "She talked to me in people talk instead of doctor talk". This type of relationship enables the women to make decisions and have control over the direction of their health care.

Finally, because the women who have been hospitalized

for HIV related concerns have had negative experiences with the hospital staff, it may be important for the health care professionals to examine their fears and misconceptions. Perhaps if the staff were aware and sensitized to the women's concerns and subsequent negative experiences, such unamiable feelings would not be present and the women's hospital stay would be less stressful. Perhaps the rigorous safety precautions are bred out of unnecessary fear of infection in which case examining personal and professional fears, biases, and prejudice about HIV/AIDS would be beneficial to staff and patients alike. These seminars could also inform the professionals as to the unique needs of women in the health care system.

Conclusion

The focus of this research was on describing the phenomenon of HIV positive women's experiences in health care. The similarity of the women's experiences and subsequent themes were powerful, yet precious because of the distinct and unique presence that each woman imparted to the research. It is hoped that these themes will inspire further research into this needed area and allow for effective changes in the health care of HIV positive women.

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APPENDIX A
Study Description and Informed Consent

This research is being done for a Master's thesis in the Educational Psychology department at the University of Alberta. This particular project is a descriptive, exploratory study which I hope will provide a better understanding of the psychological and health care needs of HIV-positive women. By meeting with the participants I hope to increase my understanding of their experiences of living as an HIV-positive women.

My concern for this area has stemmed from various endeavours. First, I have been actively involved with the local AIDS Network in my home town for many years. Second, only recently has there been available research and literature about HIV-positive women and women with AIDS and even less research on the actual experiences of women in the health care system and whether the needs of HIV-positive women are being satisfied. I am interested in doing a exploratory study in this area to ensure that the needs of present and future HIV-infected women are being fulfilled.

Participation in this study will involve two meetings. The first meeting will allow the participant and I to get to know one another. I can share my background with her, and she can share hers with me. In this meeting, I will also conduct the interview in which I will ask the participant to describe her experiences in as much detail as possible. There is no right or wrong way of telling her story, just as it comes to mind. I am more interested in her actual experiences rather than how she may have analyzed them. This interview will be tape recorded and later transcribed using pseudonyms for the participant's name and any names she may mention. Only myself and my supervisor will have access to the original tape and this tape will be destroyed once the research is completed. I will analyze the transcribed interview and identify themes which seem to represent the experiences of the participant.

The second meeting will involve sharing my understanding of the participant's experiences with her. This time will allow the participant to provide feedback that will support or refute my analysis. My data will be altered as a result of the participant's feedback.

Again, participation is voluntary and the participant is free to discontinue at any time. If she decides to discontinue, all information about her will be destroyed. If a participant should require support due to the nature of this project, I will refer her to appropriate resources. It is hoped that the project will be a positive experience for both the participant and the researcher.

APPENDIX B

INFORMED CONSENT

I, _____, give my consent to participate in Jill Turner's study. I am aware that the nature of this study is to understand the experiences of being an HIV-positive woman in the health care system, and I will be asked to describe my own experiences in as much detail as possible. I understand that the results of this interview will be published as Jill's thesis for her Master of Education degree, under the supervision of Dr. B. Paulson, in the department of Educational Psychology at the University of Alberta.

I am aware that my consent is voluntary and I can choose to opt out of this study at any time without penalty. I understand that my participation will involve two meetings which will last approximately 60 minutes in length. I am also aware that this interview will be tape recorded and that my identity, and that of any people I may mention, will be kept confidential and that Jill will be the only person who will know my real name. Also, I and any others that I may mention will be given pseudonyms to protect my identity and the identity of others.

I understand that the tape recordings will be erased when Jill has completed the transcript. I am aware that the interview transcript may be included in the appendices of the thesis. Also, I understand that if my participation in this study raises any concerns for me, Jill will suggest individuals that I might contact for support and counselling.

Signature: _____

Date: _____

APPENDIX C

Interview Questions

1. What have been your experiences as an HIV positive woman in the health care system? Mental and Physical

2. What has been the **most** useful health care service for you? I.e., Mental Health, Social Services, AIDS Network, Family Services.... (How has it been helpful)
   What has been the least useful.....

3. Where do you go for support?

4. Have you felt support from health care services? In what way?
   Have you felt opposition from health care services?

5. What are helpful qualities or attributes that you see in health care providers? (Physicians, counsellors)
   Relationship qualities?
   What are **not** helpful qualities in health care providers?

6. Have you been satisfied with your health (medical) care? (emotional)

7. Has the health care system responded to your needs, health or otherwise? (physical, emotional)

8. Have you tried alternative therapies such as herbs, vitamin supplements, massage...?

9. What would you like to see change? Different?

10. If you're hospitalized, what are your concerns for your self and your family?

11. What are the requirements for good emotional health?
    Does emotional health impact your physical health?
    What kind of role do you take in your medical care? (I.e.,discussing treatment and making decisions)
    Holistic treatment? Mind, body and spirit

Table 1

Illustration of Thematic Analysis of Woman's Experience

Protocol Excerpt	Paraphrase	Theme
401..and my GP was really helpful, my GP was very...supportive, and so she was very comforting because she knew how much of a shock it was.	Acknowledges that her physician was helpful, supportive, and comforting as GP recognized the disturbing nature of the diagnosis.	Appreciation of a supportive physician during time of diagnosis.
402. And I was really fortunate because I knew that I had some really good support.	Feeling thankful at time of diagnosis as she had a strong support network.	Feeling fortunate with her support at time of diagnosis.
403. ...and then she said "If you don't, if you discover that the support system isn't there for you, then don't forget the (organization), and that's all she said, she didn't give me a whole bunch of stuff, you know, she didn't give me a whole bunch of information.	Physician suggested alternate means of support and was sensitive to not overwhelm her with too much information.	Appreciation of physician's succinct advice and sensitivity at time of diagnosis.

Table 2

First Order Clusters of HIV Positive Woman's Experiences with Health Care

Thematic Clusters	Generalized Descriptions
1. Self-direction and personal responsibility. (114, 115, 131, 238, 333, 343, 411, 419, 427, 533, 534, 535)	They do not concern themselves or get pulled down by others' views and reactions to them. There is no desire to please others. They are unwilling to surrender their personal power to physicians and some will seek a new physician if they feel it is necessary to maintain their personal power. Some want to take care of themselves and will not relinquish control to a physician. Welcomes the sense of personal responsibility and empowerment and are accountable for life choices and experiences.
2. Active role in health care. (110, 111, 112, 124, 125, 210, 213, 237, 311, 324, 329, 330, 408, 409, 410, 412, 415, 418, 420, 423, 504, 513, 517, 518, 538, 540, 541, 542)	It is important to have control by being actively involved in personal health care decisions. They want to be informed consumers of medical treatment and be given choices and options in their health care plan. Although some women feel the disease has ultimate control over their body, they maintain some control by managing their health care. These women advocate on their own behalf to ensure their health needs are met.
3. Reactions in the face of death. (118, 120, 126, 128, 132, 134, 215, 216, 217, 218, 224, 229, 232, 233, 220, 231, 234, 342, 347,	The varying reactions to the disease may fall along a continuum of responses as some women tend to avoid the diagnosis by not thinking about it or believing that their young age and healthiness make it

348, 350, 352, 446, 443)	easy to dismiss the diagnosis. Others believe that the diagnosis has been an impetus for positive change and can maintain optimism while accepting the diagnosis. In a sense, facing death has created opportunity for life. Some women are amenable to alternative therapies while others find it too much of a hassle. Dependency foreshadows death for one woman and as a result, physical limitations are an omen of a shortened life-time.
4. Accessibility of health care. (207, 211, 221, 318, 319, 324, 327, 438, 509, 515, 521, 522)	Lack of accessible medical support and information can create fear and frustrations. For some women, health care can only be accessed if child care is provided. Some appreciate the free access to knowledgeable physicians and the clinics that provide access to a range of health care providers.
5. Mind-body relationship. (129, 223, 230, 335, 341, 345, 421, 422, 528, 529, 530)	Emotional health can positively influence physical health. It is important to think about being healthy and to maintain an optimistic, hopeful attitude to be physically healthy. The likelihood of having positive physical effects from medication is increased if one can emotionally accept the medication.
6. Family impact. (133, 326, 351, 353, 354, 430, 431, 432, 433, 435, 437, 439, 440, 441, 523, 524)	Some women recognize that their health may suffer due to inadequate child care support and that they will not seek health care if they are not assured that their children are looked after. Their personal health is secondary to that of children's health and well-being. Health may also suffer as it is difficult to ask for help with the children as it may signify that she can not control everything and may

	be viewed as a admission that she can not cope. Instead, she tries to cope alone and may become exhausted and stressed which may impact her health. However, other women take comfort in the fact that they know their children will be looked after if they need to be hospitalized. Family impact for some means that their concerns for children may hinder the desire to publicly speak about their experiences.
7. Need for compassionate medical care. (106, 107, 201, 204, 225, 228, 302, 312, 314, 321, 401, 403, 434, 436, 510, 525, 526)	Some women feel that they are not seen as a whole person as physicians' do not know anything about the women and their lives. Not seeing the women as persons results in fragmented health care and inappropriate advice. They are not viewed as people with responsibilities and physicians' are not sympathetic to their situations (i.e., children). At time of diagnosis, some women felt alone as physician was not a source of comfort or emotional support, however, some women appreciated their physicians' genuine sensitivity and support. Appreciation for physician's comfort during a crisis and the importance of having an emotionally supportive and respectful physician is just as important as having an intelligent and knowledgable physician.
8. Common Ground: Importance of validating and normalizing experiences. (119, 226, 235, 322, 323, 325, 349, 425, 426, 511, 512, 536)	It is important to be with others who have similar experiences and who can validate and normalize personal experiences. There is a desire to be with people who have had similar experiences and to share and learn with these others. Support groups offer information, education, and support to some women, while one woman stopped attending a support group as she felt it had a rivalling atmosphere (i.e., who is more ill).

9. Caring for emotional self. (121, 127, 130, 208, 219, 222, 239, 240, 337, 338, 339, 340, 344, 346, 402, 424, 428, 442, 527, 531, 532, 537, 539)	Emotional health is maintained by supportive environment of family and friends. Recognizes the importance of having someone to talk to and to help cope and remain optimistic. Some women utilize therapy as a means of support. In addition, some women are learning to care for themselves to ensure their needs are met. Some appreciate that emotional well-being is a way of life and can lead to peacefulness.
10. HIV status may be unwillingly disclosed in hospital. (102, 104, 105, 309, 331, 332, 445)	Choice around disclosure of HIV status is taken away as a blood precautions signs are put on patients' room which may inadvertently inform visitors as to their status. Additional health care staff may be informed of HIV status although they may not have any contact with the patient.
11. Health care professionals' attitudes and actions may thwart healing. (123, 202, 206, 209. 212, 236, 303, 310, 315, 320, 328, 336, 404, 405, 406, 407, 429, 444, 501, 502, 516)	Health care providers express ignorant attitudes about HIV related issues which in turn may compromise health care. Physician makes unfair assumptions about intelligence and ability of patient. Physicians have been a source of improper and inadequate information and have made erroneous predictions about life expectancy without regard for blood tests.
12. Stigma of HIV impacts treatment in hospital. (101, 103, 113, 116, 117, 205, 301, 304, 305, 306, 307, 308)	Some women experience anger and frustration during hospitalization as a result of differential and atypical treatment. Certain hospital procedures seem to be a result of fear. Some women experienced different rules than other new moms in the hospital and were not permitted to care for their newborn in the manner that they would have appreciated.

13. Healing qualities in physicians. (108, 109, 122, 203, 214, 227, 313, 316, 317, 334, 413, 414, 416, 417, 503, 505, 506, 507, 508, 514, 519, 520, 543)	A physician who can communicate in a non-patronizing tone and is a good listener is helpful. It is important to have a physician who is educated around HIV related issues and is willing to consult and find additional information about the disease. There is an appreciation for the physician who makes him/herself available regardless of the time of day and will take the time to discuss concerns. Appreciation for an egalitarian relationship.

Table 3

Second Order Clusters of HIV Positive Women's Experiences with Health Care

1. Nature of Health Care

A) Stigma of HIV impacts treatment in hospital

B) Health care professionals' attitudes and actions may thwart healing

C) Unwilling disclosure of HIV status in hospital

D) Accessibility of health care

E) Need for Compassionate medical care

F) Healing qualities in physicians

2. Importance of Support and Emotional Health

A) Common Ground: Importance of validating and normalizing experiences

B) Caring for emotional self

C) Family impact

3. Wilful Living: Self-Determination

A) Mind-body relationship

B) Self-direction and personal responsibility

C) Taking active role in health care

D) Reactions in the face of death